

Follow-Up Form
Sarcoma (SARC)

Instructions: *The Follow-up Form is to be completed 12 months after a case enters the Biospecimen Core Resource (BCR). All information provided on this form includes activity from the "Date of Last Contact" provided on the TCGA Enrollment Form to the most recent date of contact with the patient. This form should only be completed by the Tissue Source Site if updated information can be provided to TCGA. Please direct any questions to the Clinical Outreach team at the BCR.*

Please note the following definitions for the "Unknown" and "Not Evaluated" answer options on this form.

Unknown: This answer option should only be selected if the TSS does not know this information after all efforts to obtain the data have been exhausted. If this answer option is selected for a question that is part of the TCGA required data set, the TSS must complete a discrepancy note providing a reason why the answer is unknown.

Not Evaluated: This answer option should only be selected by the TSS if it is known that the information being requested cannot be obtained. This could be because the test in question was never performed on the patient or the TSS knows that the information requested was never disclosed.

Tissue Source Site (TSS): _____ TSS Identifier: _____ TSS Unique Patient Identifier: _____

Completed By (Interviewer Name on OpenClinica): _____ Completed Date: _____

General Information

#	Data Element	Entry Alternatives	Working Instructions
1	Is this Patient Lost to Follow-up?	<input type="checkbox"/> Yes <input type="checkbox"/> No	Indicate whether the patient is lost to follow-up, as defined by the ACoS Commission on Cancer. This only includes cases where updated follow-up information has not been collected within the past 15 months and all efforts to contact the patient have been exhausted (this includes reviewing the Social Security death index). If the patient is lost to follow-up, the remaining questions can be left unanswered. 61333 <i>If the patient is deceased and a TCGA follow-up form has not yet been completed, the answer to this question should be "no," and the remaining applicable questions should be completed.</i>

Follow-Up Information

#	Data Element	Entry Alternatives	Working Instructions
2	Adjuvant (Post-Operative) Radiation Therapy	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient had adjuvant/ post-operative radiation therapy <i>for the tumor submitted for TCGA</i> . 2005312 <i>If the patient did have adjuvant radiation, the Radiation Supplemental Form should be completed.</i>
3	Adjuvant (Post-Operative) Pharmaceutical Therapy	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient had adjuvant/ post-operative pharmaceutical therapy <i>for the tumor submitted for TCGA</i> . 3397567 <i>If the patient did have adjuvant pharmaceutical therapy, the Pharmaceutical Supplemental Form should be completed.</i>
4	Tumor Status <i>(at time of last contact or death)</i>	<input type="checkbox"/> Tumor free <input type="checkbox"/> With tumor <input type="checkbox"/> Unknown	Indicate whether the patient was tumor/disease free at the date of last contact or death. 2759550
5	Vital Status <i>(at date of last contact)</i>	<input type="checkbox"/> Living <input type="checkbox"/> Deceased	Indicate whether the patient was living or deceased at the date of last contact. 5
6	Month of Last Contact	<input type="checkbox"/> 01 <input type="checkbox"/> 04 <input type="checkbox"/> 07 <input type="checkbox"/> 10 <input type="checkbox"/> 02 <input type="checkbox"/> 05 <input type="checkbox"/> 08 <input type="checkbox"/> 11 <input type="checkbox"/> 03 <input type="checkbox"/> 06 <input type="checkbox"/> 09 <input type="checkbox"/> 12	If the patient is living, provide the month of last contact with the patient (as reported by the patient, medical provider, family member, or caregiver). 2897020

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#	Data Element	Entry Alternatives	Working Instructions
7	Day of Last Contact	<input type="checkbox"/> 01 <input type="checkbox"/> 08 <input type="checkbox"/> 14 <input type="checkbox"/> 20 <input type="checkbox"/> 26 <input type="checkbox"/> 02 <input type="checkbox"/> 09 <input type="checkbox"/> 15 <input type="checkbox"/> 21 <input type="checkbox"/> 27 <input type="checkbox"/> 03 <input type="checkbox"/> 10 <input type="checkbox"/> 16 <input type="checkbox"/> 22 <input type="checkbox"/> 28 <input type="checkbox"/> 04 <input type="checkbox"/> 11 <input type="checkbox"/> 17 <input type="checkbox"/> 23 <input type="checkbox"/> 29 <input type="checkbox"/> 05 <input type="checkbox"/> 12 <input type="checkbox"/> 18 <input type="checkbox"/> 24 <input type="checkbox"/> 30 <input type="checkbox"/> 06 <input type="checkbox"/> 13 <input type="checkbox"/> 19 <input type="checkbox"/> 25 <input type="checkbox"/> 31 <input type="checkbox"/> 07	If the patient is living, provide the day of last contact with the patient (as reported by the patient, medical provider, family member, or caregiver). 2897022
8	Year of Last Contact	_____	If the patient is living, provide the year of last contact with the patient (as reported by the patient, medical provider, family member, or caregiver). 2897024
9	Month of Death	<input type="checkbox"/> 01 <input type="checkbox"/> 04 <input type="checkbox"/> 07 <input type="checkbox"/> 10 <input type="checkbox"/> 02 <input type="checkbox"/> 05 <input type="checkbox"/> 08 <input type="checkbox"/> 11 <input type="checkbox"/> 03 <input type="checkbox"/> 06 <input type="checkbox"/> 09 <input type="checkbox"/> 12	If the patient is deceased, provide the month of death. 2897026
10	Day of Death	<input type="checkbox"/> 01 <input type="checkbox"/> 08 <input type="checkbox"/> 14 <input type="checkbox"/> 20 <input type="checkbox"/> 26 <input type="checkbox"/> 02 <input type="checkbox"/> 09 <input type="checkbox"/> 15 <input type="checkbox"/> 21 <input type="checkbox"/> 27 <input type="checkbox"/> 03 <input type="checkbox"/> 10 <input type="checkbox"/> 16 <input type="checkbox"/> 22 <input type="checkbox"/> 28 <input type="checkbox"/> 04 <input type="checkbox"/> 11 <input type="checkbox"/> 17 <input type="checkbox"/> 23 <input type="checkbox"/> 29 <input type="checkbox"/> 05 <input type="checkbox"/> 12 <input type="checkbox"/> 18 <input type="checkbox"/> 24 <input type="checkbox"/> 30 <input type="checkbox"/> 06 <input type="checkbox"/> 13 <input type="checkbox"/> 19 <input type="checkbox"/> 25 <input type="checkbox"/> 31 <input type="checkbox"/> 07	If the patient is deceased, provide the day of death. 2897028
11	Year of Death	_____	If the patient is deceased, provide the year of death. 2897030
12	Measure of success of outcome at the completion of this follow-up submission	<input type="checkbox"/> Progressive Disease <input type="checkbox"/> Stable Disease <input type="checkbox"/> Partial Response <input type="checkbox"/> Complete Response	Indicate the patient's measure of success at the time this follow-up form is completed. 3033278

New Tumor Event Information Complete this section if the patient had a new tumor event. If the patient did not have a new tumor event (or if the TSS does not know) indicate this in the question below, and the remainder of this section can be skipped.

Note: The New Tumor Event section on OpenClinica can be completed multiple times, if the patient had multiple New Tumor Events.

#	Data Element	Entry Alternatives	Working Instructions
13	New Tumor Event After Initial Treatment?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient had a new tumor event (e.g. metastatic, recurrent, or new primary tumor) after the date of initial diagnosis. 3121376
14	Type of New Tumor Event	<input type="checkbox"/> Locoregional/Recurrence <input type="checkbox"/> Distant Metastasis <input type="checkbox"/> New Primary Tumor	Indicate whether the patient's new tumor event was a locoregional recurrence, a distant metastasis or a new primary tumor. 3119721
15	Site of New Tumor Event	<input type="checkbox"/> Lung <input type="checkbox"/> Brain <input type="checkbox"/> Bone <input type="checkbox"/> Unknown <input type="checkbox"/> Liver <input type="checkbox"/> Other, specify	Indicate the site of this new tumor event. 3108271
16	Other Site of New Tumor Event	_____	If the patient had a new tumor event and the site of this tumor was not included in the provided list, describe the site. 3128033
<i>Date of New Tumor Event after Initial Treatment</i>			
17	Month of New Tumor Event	<input type="checkbox"/> 01 <input type="checkbox"/> 04 <input type="checkbox"/> 07 <input type="checkbox"/> 10 <input type="checkbox"/> 02 <input type="checkbox"/> 05 <input type="checkbox"/> 08 <input type="checkbox"/> 11 <input type="checkbox"/> 03 <input type="checkbox"/> 06 <input type="checkbox"/> 09 <input type="checkbox"/> 12	If the patient had a new tumor event, provide the month of diagnosis for this new tumor event. 3104044
18	Day of New Tumor Event	<input type="checkbox"/> 01 <input type="checkbox"/> 08 <input type="checkbox"/> 14 <input type="checkbox"/> 20 <input type="checkbox"/> 26 <input type="checkbox"/> 02 <input type="checkbox"/> 09 <input type="checkbox"/> 15 <input type="checkbox"/> 21 <input type="checkbox"/> 27 <input type="checkbox"/> 03 <input type="checkbox"/> 10 <input type="checkbox"/> 16 <input type="checkbox"/> 22 <input type="checkbox"/> 28 <input type="checkbox"/> 04 <input type="checkbox"/> 11 <input type="checkbox"/> 17 <input type="checkbox"/> 23 <input type="checkbox"/> 29 <input type="checkbox"/> 05 <input type="checkbox"/> 12 <input type="checkbox"/> 18 <input type="checkbox"/> 24 <input type="checkbox"/> 30 <input type="checkbox"/> 06 <input type="checkbox"/> 13 <input type="checkbox"/> 19 <input type="checkbox"/> 25 <input type="checkbox"/> 31 <input type="checkbox"/> 07	If the patient had a new tumor event, provide the day of diagnosis for this new tumor event. 3104042

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#	Data Element	Entry Alternatives	Working Instructions	
<u>19</u>	Year of New Tumor Event	_____	If the patient had a new tumor event, provide the year of diagnosis for this new tumor event. 3104046	
<u>20</u>	Additional Surgery for New Tumor Event	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Using the patient's medical records, indicate whether the patient had surgery for the new tumor event in question. 3427611	
<i>Date of Additional Surgery for New Tumor Event (when applicable)</i>				
<u>21</u>	Month of Additional Surgery for New Tumor Event	<input type="checkbox"/> 01 <input type="checkbox"/> 04 <input type="checkbox"/> 07 <input type="checkbox"/> 10 <input type="checkbox"/> 02 <input type="checkbox"/> 05 <input type="checkbox"/> 08 <input type="checkbox"/> 11 <input type="checkbox"/> 03 <input type="checkbox"/> 06 <input type="checkbox"/> 09 <input type="checkbox"/> 12	If the patient had surgery for the new tumor event, provide the month this surgery was performed. 3427612	
<u>22</u>	Day of Additional Surgery for New Tumor Event	<input type="checkbox"/> 01 <input type="checkbox"/> 08 <input type="checkbox"/> 14 <input type="checkbox"/> 20 <input type="checkbox"/> 26 <input type="checkbox"/> 02 <input type="checkbox"/> 09 <input type="checkbox"/> 15 <input type="checkbox"/> 21 <input type="checkbox"/> 27 <input type="checkbox"/> 03 <input type="checkbox"/> 10 <input type="checkbox"/> 16 <input type="checkbox"/> 22 <input type="checkbox"/> 28 <input type="checkbox"/> 04 <input type="checkbox"/> 11 <input type="checkbox"/> 17 <input type="checkbox"/> 23 <input type="checkbox"/> 29 <input type="checkbox"/> 05 <input type="checkbox"/> 12 <input type="checkbox"/> 18 <input type="checkbox"/> 24 <input type="checkbox"/> 30 <input type="checkbox"/> 06 <input type="checkbox"/> 13 <input type="checkbox"/> 19 <input type="checkbox"/> 25 <input type="checkbox"/> 31 <input type="checkbox"/> 07	If the patient had surgery for the new tumor event, provide the day this surgery was performed. 3427613	
<u>23</u>	Year of Additional Surgery for New Tumor Event	_____	If the patient had surgery for the new tumor event, provide the year this surgery was performed. 3427614	
<u>24</u>	Residual Tumor after Surgery for New Tumor Event	<input type="checkbox"/> RX <input type="checkbox"/> R1 <input type="checkbox"/> R0 <input type="checkbox"/> R2	Using the patient's pathology/laboratory report, select the residual tumor status after the surgical resection for the new tumor event. 3104061	
<u>25</u>	Is the New Disease Multifocal?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Using the patient's pathology/laboratory report, indicate whether the new tumor was multifocal. 3524937	
<u>26</u>	Number of Discontiguous Lesions (New Tumor Event)	_____	Using the patient's pathology/laboratory report, provide the number of discontiguous lesions for the new tumor. 3526717	
<u>27</u>	Radiologic Size of New Tumor	Radiologic Length	_____ (cm)	Provide the length for the new tumor, when available as reported on the CT scan or MRI, immediately preceding the surgical resection of the new tumor. 3527990
		Radiologic Width	_____ (cm)	Provide the width for the new tumor, when available as reported on the CT scan or MRI, immediately preceding the surgical resection of the new tumor. 3527997
		Radiologic Depth	_____ (cm)	Provide the depth for the new tumor, when available as reported on the CT scan or MRI, immediately preceding the surgical resection of the new tumor. 3527996
<u>28</u>	Pathologic Size of New Tumor	Pathologic Length	_____ (cm)	Provide the length for the new tumor, when available as examined pathologically at the time of the surgical resection of the new tumor. 3528003
		Pathologic Width	_____ (cm)	Provide the width for the new tumor, when available as examined pathologically at the time of the surgical resection of the new tumor. 3528020
		Pathologic Depth	_____ (cm)	Provide the depth for the new tumor, when available as examined pathologically at the time of the surgical resection of the new tumor. 3528004
<u>29</u>	Radiologic Burden of New Tumor	_____	Provide the sum of the maximum diameter of the new tumors as reported on the CT scan or MRI immediately preceding surgical resection. This should include both well-differentiated and de-differentiated components. 3562720	
<u>30</u>	Pathologic Burden of New Tumor	_____	Provide the sum of the maximum diameter of the new tumors as examined pathologically at the time of the surgical resection. This should include both well-differentiated and de-differentiated components. 3526721	

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#	Data Element	Entry Alternatives	Working Instructions
31	Is the New Tumor Well-Differentiated or De-Differentiated? <i>(Check all that apply)</i>	<input type="checkbox"/> Well-Differentiated <input type="checkbox"/> De-Differentiated	Indicate whether the newly diagnosed tumor is well-differentiated or de-differentiated. 3194001
32	Additional treatment for New Tumor Event: <i>Radiation Therapy</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient received radiation treatment for this new tumor event. 3427615
33	Additional treatment for New Tumor Event: <i>Pharmaceutical Therapy</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient received pharmaceutical treatment for this new tumor event. 3427616
Time Intervals: The following questions are only to be answered if the Tissue Source Site is unable to provide the dates requested on this form. <i>Please Note: Only provide interval data if you have received permission from the NCI to provide time intervals as a substitute for requested dates on this form.</i>			
i	Has this TSS received permission from the NCI to provide time intervals as a substitute for requested dates on this form?	<input type="checkbox"/> Yes <input type="checkbox"/> No	Please Note: The time intervals must be recorded in place of dates where designated throughout this form if you have selected "yes" in the box. Provided time intervals must begin with the date of initial pathologic diagnosis (i.e., biopsy or resection).
ii	Number of Days from Date of Initial Pathological Diagnosis to Date of Last Contact	_____ days	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease described on this form to the date of last contact. 3008273
iii	Number of Days from Date of Initial Pathological Diagnosis to Date of Death	_____ days	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease described on this form to the date of death 3165475
iv	Number of Days from Date of Initial Pathological Diagnosis to Date of New Tumor Event After Initial Treatment	_____ days	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease to the date of new tumor event after initial treatment. 3392464
v	Number of Days from Date of Initial Pathologic Diagnosis to Date of Additional Surgery for New Tumor Event	_____ days	Provide the number of days from date of initial pathologic diagnosis to date of additional surgery for new tumor event 3008335

 Principal Investigator or Designee Signature

 Print Name

 ____/____/_____
 Date

I acknowledge that the above information provided by my institution is true and correct and has been quality controlled.